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# Systematising the care of long-term conditions: the Year of Care model

*Pieter Degeling, Helen Close and Deidre Degeling*

The World Health Organization defines long-term conditions as ‘health problems that require ongoing management over a period of years or decades’.<sup>1</sup> Long-term conditions have significant deleterious effects on the lives of patients and their carers, the health care system, and society at large.<sup>2</sup> In the UK over 17 million people, including perhaps two thirds of those over 65, have one or more of these conditions.<sup>3</sup>

Specific impacts of long-term conditions are registered on the lives and bodies of people with the conditions and their families, carers and the health and social care system itself. Conditions are associated with physical discomfort, disability and uncertainty, reduced earning capacity, poor quality of life, and a high risk of developing comorbidities including in mental health.<sup>4</sup>

Many people with long-term conditions depend on the support of family members and other informal carers. These informal carers suffer proportionately more health problems than other people of the same age, particularly in regard to back problems and long-term mental health problems such as depression. In such complex situations crisis management becomes the norm, resulting in poor quality of life and clinical outcomes and high health service utilisation by the initial care recipient and the informal caregiver.<sup>5</sup>

The size and complexity of the problems needing to be addressed by the health and social care system have only recently been recognised. The evidence suggests that up to 80% of primary care consultations and 66% of emergency hospital admissions in Britain involve people with long-term conditions.<sup>6</sup> Our recent analysis of Hospital Episode Statistics (HES), suggests that in England 18 of the top 40 HRGs, accounting for 45% of accident and emergency admissions, reference long-term conditions with a high risk of repeat emergency admission.<sup>7</sup> Within Wales, over the past 10 years, ‘two thirds of patients admitted as medical emergencies have a chronic condition or have a worsening chronic condition’.<sup>8</sup>

Thus, the quality, effectiveness, appropriateness and efficiency of service

provision to people with long-term conditions has become a major challenge for health and welfare systems in the developed world. Despite accumulating evidence about service shortcoming and a procession of government initiatives for service improvement, our understanding of systematic ways of meeting the care needs of people with long-term conditions remains inadequate. This chapter critically examines some proposals to overcome gaps between promise and performance and outlines the essential features of a Year of Care (YoC) programme. We discuss how this might be applied in systematising the design, commissioning and delivery of services to people with long-term conditions as well as informing the 'time specified' care plan that they have negotiated with primary care-based service providers.

## CHARACTERISTICS OF LONG-TERM CONDITIONS AND THEIR IMPLICATIONS FOR SERVICE REDESIGN

Three underlying attributes characterise long-term conditions. First they are deteriorative; thus the aetiology and prognosis of a person with a long-term condition indicates how far the condition has progressed at a given point in time.<sup>9</sup> This characteristic implies that for any individual with such a condition the composition of the service will change as the physical and psychological manifestations of the condition deteriorates and/or as the personal priorities change.

Second, while a long-term condition affects an individual's life, it does not define them, particularly in how they see and project themselves in their work, their relationships with loved ones, and other aspects of their lives. Thus, people with these conditions place continuing emphasis on maintaining control over what is significant in their daily lives.<sup>10</sup> This emphasis signifies the importance of devising and implementing service models that are structured to underwrite the voice and volition of people with long-term conditions and

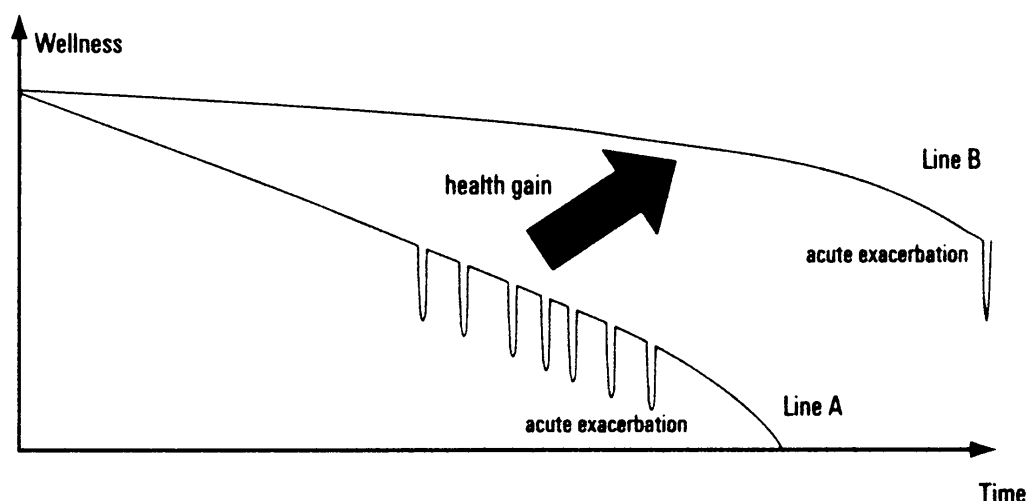


FIGURE 9.1 Wellness trajectory

hints at the shortcomings that arise when services are construed primarily in clinical terms.

Third, within an individual's genetic predispositions, the onset and subsequent rate of progression of some long-term conditions (such as heart disease, COPD, diabetes) are to a significant degree outcomes of how risks inherent in an individual's personal, social and economic circumstances as well as lifestyle impact on that person's health.<sup>11</sup> Possible clinical effects of this characteristic are displayed in Figure 9.1 which depicts two possible trajectories of wellness over time: rapid decline (Line A) and delayed decline (Line B). The differences between A and B are important for the lives of people and how services are designed and implemented. In very direct and immediate ways the differences underline the individual's position as self-manager of health and thus of the onset and rate of progression of a condition. However the differences also imply personal and socioeconomic factors that affect an individual's capacity to reduce lifestyle and related risks and which service modalities may need to accommodate.

## MODELS OF LONG-TERM CARE

Several models have been proposed to meet these challenges. The aim has been to devise structures and methods that meet the defining features of primary care (continuity, coordination, and comprehensiveness)<sup>12</sup> and provide guidance on how services should be configured to the benefit of improved quality of care, improved quality of life, and increased cost-effectiveness.

One much cited model is Wagner's Chronic Care Model depicted in Figure 9.2 below (also shown in Figure 2.1). Its strengths lie in its identification of the range of factors to be taken into account in designing a service that is appropriate to people with long-term conditions (such as the centrality of informed and active patients, responsive community resources, and proactive primary care teams). Its shortcomings are its lack of guidance on how these design features might be realised on the ground that is, the features to bring together complex clinical treatment regimes, the support that will enable individuals (located at different points of the downward progression of their condition) to take an active role in managing their own care, and the commissioning, monitoring and management requirements of the care services.

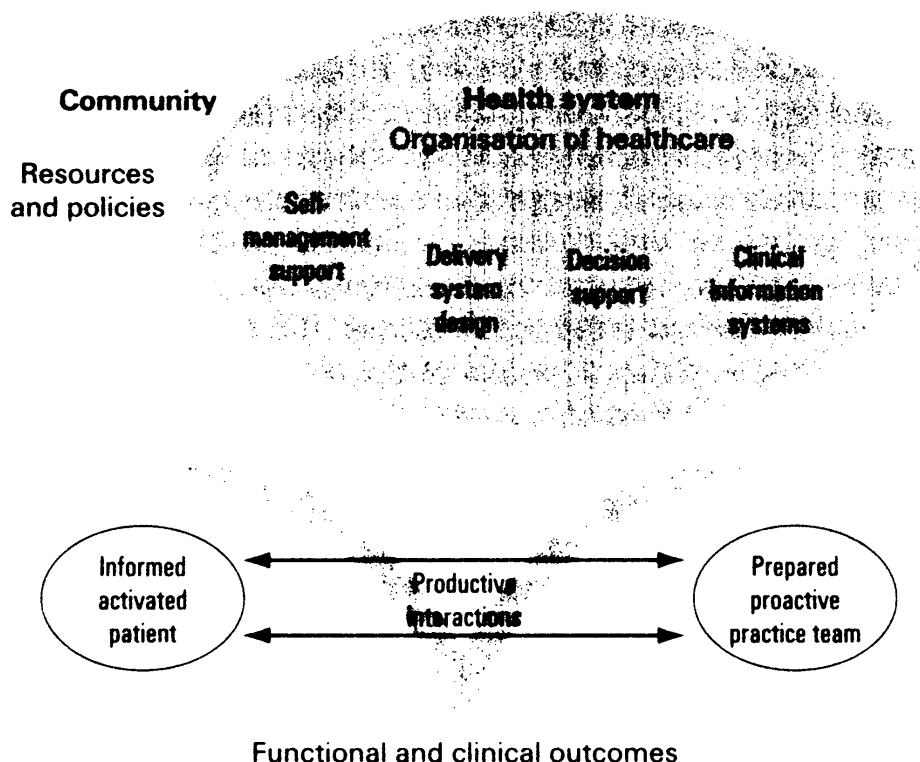
A starting point for filling these gaps is the NHS and Social Care Long-term Conditions Model, promulgated in January 2005, along lines displayed in Figure 9.3. Adapting aspects of a model first used by Kaiser Permanente in the USA, the model proposes three levels of need and care: (1) self-management, (2) care management and (3) complex case management.<sup>14</sup> It provides for a more systematised approach to service provision, specifically detailed descriptions of care modalities that, for each identified level of need, are:

- ▶ prospectively designed with a proactive rather than an emergent and reactive orientation

- explicitly defined, planned and coordinated rather than implicit and unplanned
- capable of focusing on the health risks of identified populations and the changing wishes and priorities of people with long-term conditions
- capable of being collaboratively designed and implemented rather than imposed
- structured to facilitate routine review in ways that will engender improved experiences of people with long-term conditions and improved service quality, outcomes and cost.

Enunciating a set of desired attributes, however, does not guarantee their attainment. In the case of service to people with long-term conditions, successful implementation will depend on the presence or absence of a range of integrating structures and methods, specifically:

- *explicit methodologies* for (1) stratifying the populations of people that fall within the ambit of specified long-term conditions and (2) for identifying their health risks as well as their wants and priorities as they see these to be
- a *person* who is both *authorised* to integrate service provision and *accountable* for its occurrence or non-occurrence



**FIGURE 9.2** The model for improvement of chronic illness care<sup>13</sup>

- ▶ an integrating *methodology* that specifies how the identified risks and priorities of an individual will be linked with a specified menu of services from within the health service but also from other sources such as social services, the voluntary sector, community sources and informal carers
- ▶ an integrating *artefact* such as, for example, a care plan or pathway that (1) specifies who will do what, why, when and where, and (2) records the responsibilities and rights of all parties (an individual with a long-term condition, carers and service providers, etc.) can expect from each other
- ▶ an integrating *performance management and review process* that (1) routinely and systematically examines service performance in respect of its appropriateness for meeting the specific needs and wants of each population stratum and (2) sets the agenda for ongoing service improvement as defined above.

The extent to which these conditions are met in Department of Health pronouncements is set out in Table 9.1. Noteworthy is the variability of the Department's advice on the defining elements of the model in respect of both day-to-day clinical practice as well as how services will be commissioned and managed. In summary, the table illustrates shortcomings at three levels.

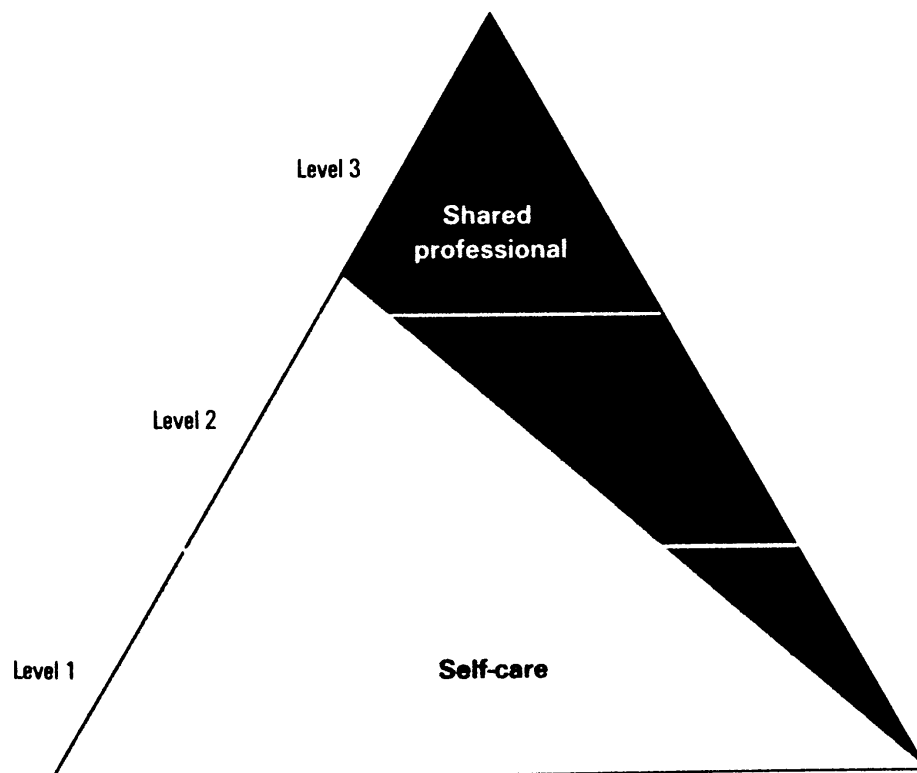


FIGURE 9.3 The NHS and Social Care Long-term Conditions Model

TABLE 9.1 Summary of prevailing NHS service models for long-term conditions

	Level 3 Case management	Level 2 Care management	Level 1 Self-management
<b>Population criteria</b>	<p><i>Highly specific</i></p> <p>Patient population identified using specific clinical indicators such as:</p> <ul style="list-style-type: none"> <li>• two or more hospital admissions</li> <li>• length of stay longer than 40 days</li> <li>• presence of comorbidities</li> <li>• in the top 3% of GP attendees</li> <li>• significant functional impairment</li> <li>• scope and stability of informal care.</li> </ul>	<p><i>No detailed specification</i></p> <p>A general statement that the population comprises patients with a single condition or range of problems who would benefit from care management.</p>	<p><i>Not specified</i></p> <p>The boundary criterion for differentiating between the Level 1 population and the total population is not defined; rather, the self-care population is construed as an undifferentiated group traversing all three levels.</p>
<b>Identified primary integrator</b>	<p><i>Community matron</i></p> <ul style="list-style-type: none"> <li>• with authority to order clinical investigations, make referrals and arrange admissions to hospital</li> <li>• who is the fixed point of contact for the patient</li> <li>• coordinates contributions of other professionals and agencies.</li> </ul>	<p><i>A primary care clinician</i></p> <p>Any nominated member of a multidisciplinary team who:</p> <ul style="list-style-type: none"> <li>• acts as a point of contact between the patient and team</li> <li>• helps patient to navigate services.</li> </ul>	<p><i>Not specified</i></p> <p>No clear statements about who will do what, when and where.</p>
<b>Service aim</b>	<p>To reduce repeat admissions and improve quality of life.</p>	<p>To slow down disease progression, reduce disability, ensure better management of deteriorations, reduce need for hospital admission and improve quality of life.</p>	<p><i>Not specified</i></p> <p>Rather, attention is given to specifying the tasks of self-managing patients across all levels of care.</p>
<b>Method</b>	<p><i>Case management</i></p> <ul style="list-style-type: none"> <li>• planned to occur along lines that explicitly recognise current need and anticipates future need on a patient by patient basis</li> <li>• emergent variations managed by the community matron as case manager.</li> </ul>	<p><i>Care management</i></p> <ul style="list-style-type: none"> <li>• Stratified, condition specific registers.</li> <li>• Time specified recall and review process.</li> <li>• Condition specific networks that span primary and acute settings.</li> <li>• Daily service provision in primary care; acute clinicians act as <i>knowledge node</i>.</li> </ul>	<p><i>Not specified</i></p> <p>Broad discussion of a range of issues and tools relating to:</p> <ul style="list-style-type: none"> <li>• information</li> <li>• skills and training</li> <li>• tools and devices</li> <li>• support networks</li> </ul>

	Level 3 Case management	Level 2 Care management	Level 1 Self-management
<b>Artefact</b>	<p><i>An individual care plan that is held and owned by patients that specifies</i></p> <ul style="list-style-type: none"> <li>• details of the care to be provided</li> <li>• regular reviews to assess need</li> <li>• self-care to be undertaken by the patient and informal carers</li> <li>• what each professional and agency will do to meet need, manage risk and/or support self-management.</li> </ul>	<p><i>Single assessment document – some mention of the use of individualised patient care plans.</i></p>	<p><i>Not specified</i></p>
<b>Performance management and review</b>	<i>Not specified</i>	<i>Not specified</i>	<i>Not specified</i>

We attribute these shortcomings, first, to the way long-term conditions are construed largely in clinical terms. Through such construction illness is taken outside the domain of the subjective experience and volition of the persons affected and they become bearers of discrete pathologies and patient dependents rather than co-producing self-managers of their health within the context of a wider life. Such clinically determined needs assessment processes more often than not exclude the voice of the individual labelled as ‘patient’ and the list of ‘patient needs’ is then, by definition, nothing more than a composite of clinical bio-physical models and understandings of what services are available.<sup>15</sup> Such constriction often leads clinicians to conspire with a ‘patient’ to mask the deteriorative character of the condition.<sup>16</sup> It also flies in the face of evidence about how an individual’s desire and/or ability to be directly involved in managing their condition and behaviour to the benefit of secondary prevention is influenced by a range of personal, psychological and socioeconomic characteristics.<sup>17</sup>

Second, the variable and limited definitions and specificities of target undermine the commissioning, evaluation and improvement of aspects of service provision for those with long-term conditions. For example, the highly detailed criteria nominated for case management (level 3) services stand in stark contrast to the broad non-specific criteria nominated for care management (level 2) and the absence of any criteria for self-management (level 1). This gradation of specificity (from highly to not specified) is also found in the structures and methods central to service integration, namely the identification of an *authorised integrator*, the specification of an integrating *methodology* and use of an *integrating artefact* that specifies who will do what, why, when



and where. Again, while for case management we are given details about the case management responsibilities of community matrons and individual care plans, the same level of detail is not evident for care management and is absent altogether for self-management. Indeed, the absence of detailed advice on the co-production aspects of what, in the model, is termed 'self-care' is a systemic weakness.

## **PRINCIPLES OF AN ALTERNATIVE MODEL**

We seek here to formulate a model for the care of those with long-term conditions that builds on the systematising developments of the models elaborated above but which first, as a matter of right, maintains the sociality of people with long-term conditions and underwrites their voice and volition, and second, clarifies the why and how of their irreducible personal responsibility for their own health.

In respect of rights, the model construes people with a long-term condition as sentient beings with aspirations, priorities and perspectives that reflect their personal histories as well as ongoing relations with significant others. Equally, the model underwrites the right and ability of these people to exercise control over what happens to them both in the here and the future. In other words we are formulating a model whose use underwrites the inherent sociality of people with a long-term condition, that recognises the web of relations in which they are embedded, that preserves their personal identities and that validates their meanings, priorities and life choices in the terms in which they make these.

On responsibility, by way of its refusal to separate the body and the self, our model explicitly recognises causal interconnections between any individual's health and their behaviour in respect of, for example, diet, smoking and other risk behaviours such as maintaining a work-life balance. We hasten to add that inclusion of this design attribute does not mean that we believe that an individual's health is solely explainable in these terms; as we have recognised above, it may be the product of genetic predispositions, or social and economic circumstances. That said, however, it is also the case that while these added factors have significant effects, they are of themselves not sufficient. Put simply, the fact that the self and the body cannot be other than coterminous it necessarily follows that an individual retains, firstly, ultimate responsibility for maintaining his or her health and, secondly, the right to be the final arbiter of what is done for and to them by others in this regard.

Viewed from this perspective it is apparent that relationships between people with long-term conditions and clinicians are appropriately construed in principal-agent terms. Within this model, people with long-term conditions retain ultimate responsibility for their health, a responsibility inscribed in their relationship (as principal) with carers (as agents) with whom they co-produce their health. Accordingly the process through which services are designed and delivered should be structured along lines that enshrine the rights and

responsibilities of people with long-term conditions to be informed, to be consulted and involved in decision making and to enter agreements with agents (clinicians and other carers) that specify what they (as principal) can expect from others and what others can expect from them.

The foregoing does not mean that the concepts of co-production, principal and agent are self-recommending. We recognise the limits set by an individual's genetic predispositions, by socioeconomic processes and circumstances and by other factors on a principal's ability to manage his or her health including by changing behaviour or complying with medication and other regimes. The standing we accord to questions such as these, however, depends on what we regard as appropriate for testing the conceptual, practical and ethical utility of models of care. By its nature, an individual's genetic and socioeconomic inheritance is very largely a personal given outside that individual's direct control. What matters is whether in enactment our proposed model restructures relations, such that people 'dealt a bad hand' by genetics and/or their socioeconomic antecedents are more empowered to exercise volition and voice in responding to the circumstances in which they find themselves.

Crucial here are the modes of structuring. As demonstrated earlier, prevailing approaches to service provision construct people with long-term conditions primarily in clinical terms. In contrast, we require a model that casts people with a long-term condition in ways that both legitimise their voices and requires that these will be not only *heard* but also *heeded* by clinicians as their agents. Within a principal-agent conception of service provision the providers (as agents) are responsible for (1) meeting the principal's right to be fully informed about the options from which they might choose and the health consequences that follow from each of these and (2) to provide support within the limits of available knowledge and resources that will enable the principal to overcome limits imposed by personal, social and economic circumstances that an individual's choice (as the principal) is one that will promote his or her health, service providers (as agents) are bounded (within the limits of available resources). Thirdly, in keeping with the underlying logic of their standing as agent, it is incumbent on service providers that they accept the validity of the choices and priorities of an individual, even when these may be counter-productive to 'good' health.

The last of these injunctions, on the agent role of service providers, will raise questions about how we construe the responsibilities of individuals whose lifestyle, habits or behaviours put them at risk of either exacerbating a long-term condition or of triggering the onset of a long-term condition. The matters at issue here swing largely on what is seen as falling within the scope of an individual's responsibility in different contexts. In the personal context, the coterminous nature of the body and the self means that, on both logical and clinical grounds, individuals necessarily retain their personal responsibility for what they do or do not do to their bodies. Equally, in an interpersonal context (i.e. depending on the level of connectedness with family and others),

individuals carry some responsibility for what they do about their personal health. At a societal level the collective interest in social and political solidarity has arranged for aspects of social care and illness treatment to be provided by the state. Under these arrangements all individuals, including those who deny their personal responsibility for acting in ways that will promote their health, retain the right to both clinical treatment and support. But we observe an increasing recognition that this right does not absolve them of responsibilities to themselves arising from the coterminosity between the body and the self.

We are well aware that the enactment of a principal/agent conception (of relationships between individuals with a long-term condition and service providers) will be much messier than our statement suggests, a result in part at least from addressing aspects of a condition's downward progression that clinically dominated models mask. Thus, the starting point for constructing the type of partnership we envisage lies with service providers addressing the whole story of what it means to live with a long-term condition; that is, not only to *look at* people with a long-term condition but also to *look with* them as well.<sup>18</sup> This will inform joint assessments of the risks that confront both individuals with long-term conditions and service providers. The reference to **risks faced by both parties** rather than **patient need** is intentional. Patient need assessment processes are self-defining mediums by which clinical and other professionals construct both 'patients' and their 'needs' in terms that fit both clinical deficits and available interventions. Accordingly, along with Reed and Clarke<sup>19</sup> we propose that what used to be termed 'needs assessment' should be broadened to identify actual and potential risks as these are construed not merely by service providers but also by the individual with a long-term condition and their informal carers.

One existing effort of this kind is the Expert Patient Program (EPP). Following principles first enunciated by Lorig, *et al.* in their Chronic Disease Self-Management programme,<sup>20</sup> EPP is a lay-led, generic programme for those with long-term conditions. It is based on the view that such people encounter similar problems whose management, when on the terms of the individual with a long-term condition rather than of service providers, will lead to improved quality of life and health status as well as reduced use of health services. Thus, in addition to strategies for clinically oriented problems such as recognising and acting on symptoms, using medication correctly, EPP also addresses psycho-social problems such as stress management and managing psychological responses to illness and, most importantly, ways in which individuals can ensure their voices are heard and heeded in interactions with clinicians. However, while EPP has been assessed as increasing self-efficacy, reducing GP visits, reducing symptoms and reducing costs, there appear to be no evaluations of how the programme has extended the voice of people with long-term conditions in its design and delivery.<sup>21</sup>

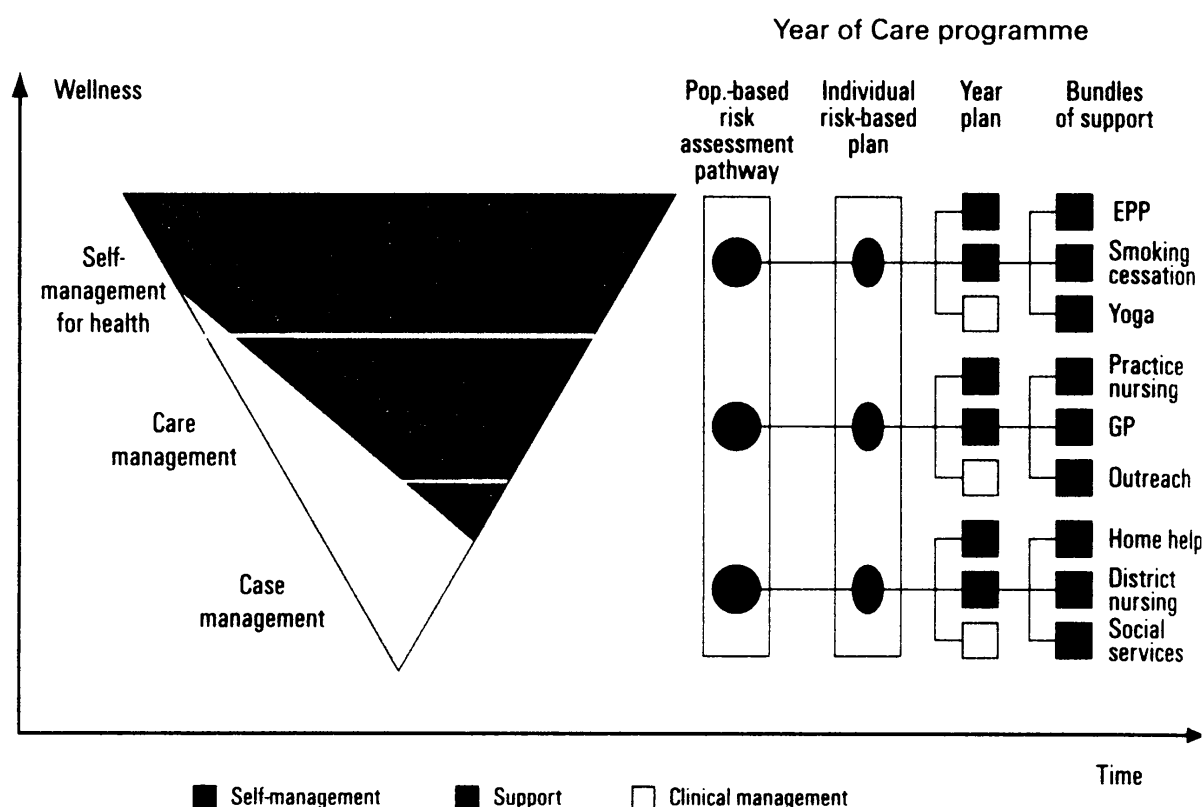
## ELEMENTS OF A YEAR OF CARE MODEL FOR LONG-TERM CONDITIONS

The constituent elements of an alternative model are illustrated in Figure 9.4. The model differs from the original Department of Health model in five ways.

- 1 In the interest of clearly delineating between people at each stage of downward progression we distinguish between three populations: those who are at risk of developing a long-term condition, those who already have a long-term condition, and those with complex (co-) morbidities.
- 2 In recognition of the way that co-production by people with a long-term condition (as principals) and carers (as agents) changes at each level of downward progression, the model proposes three service modalities (self-management for health, care management, and case management) each with a distinct profile of the expectations and responsibilities of the parties involved in service provision.
- 3 For each of these modalities, the model invites consideration of what can and needs to be done in planning and negotiating service provision at both population and individual levels.
- 4 The model extends the constituent elements of the Department of Health service model beyond *clinical* and *self-management* to also include *support* and invites detailed consideration of the types of support that will be provided at each level.
- 5 The model invites consideration of the process and outcome measures that will be used (for each service modality) to evaluate and improve its service modality.

In essence the model exhibits three systemic dimensions. First, it focuses on three populations. At the level of self-management are those people who have been identified as exhibiting risk factors that if not addressed would lead to a long-term condition and hence who would benefit from interventions that would support them in co-producing their health. Identification of this group of people will rely on GP practice-based condition specific registers that are designed to highlight individuals at high risk of developing a long-term condition. Such a system is already in existence in which GPs and other primary care staff record interventions under the Quality and Outcomes Framework which offers financial incentives for regular monitoring of blood pressure, for example. However, a system designed along lines of co-production will also need to incentivise the recording and monitoring of psycho-social assessments.

At the level of care management are those people who have been identified as having a long-term condition and hence require specified clinical management, but who do not exhibit the full range of clinical morbidities requiring specific case management, and whose psycho-social circumstances are such that, with



**FIGURE 9.4** A Year of Care model for long-term conditions (showing bundles of support)

the appropriately targeted support are able to self-manage their symptoms and, in many cases, mitigate the rate of downward progression of their condition. Again, assessment and disease specific service provision will rely on NICE and NSF related criteria, in addition to psycho-social assessment.

At the level of case management are those people with complex needs who either exhibit clinical signs and symptoms specified in the existing DoH model or whose psycho-social circumstances are such that they require enhanced support. Identification of people most likely to benefit from case management would rely on guidelines already specified in the Patients At Risk of Readmission (PARR) tool, such as two or more comorbidities, two or more hospital admissions, and length of stay longer than 40 days, as well as disease specific. As important, however, will be assessment based on psycho-social factors such as health literacy, living circumstances, and environmental factors.

Figure 9.5 depicts the cycles of risk assessment, planning, commissioning, enactment and evaluation that will characterise year pathways at the levels of case management, care management and self-management for health. Similarly, Figure 9.6 depicts the same cycle of activities for the case plan, care plan or a health plan that will be co-produced with nominated individuals.

The second systemic dimension of the model distinguishes between the risk assessment and service planning processes that will take place at different

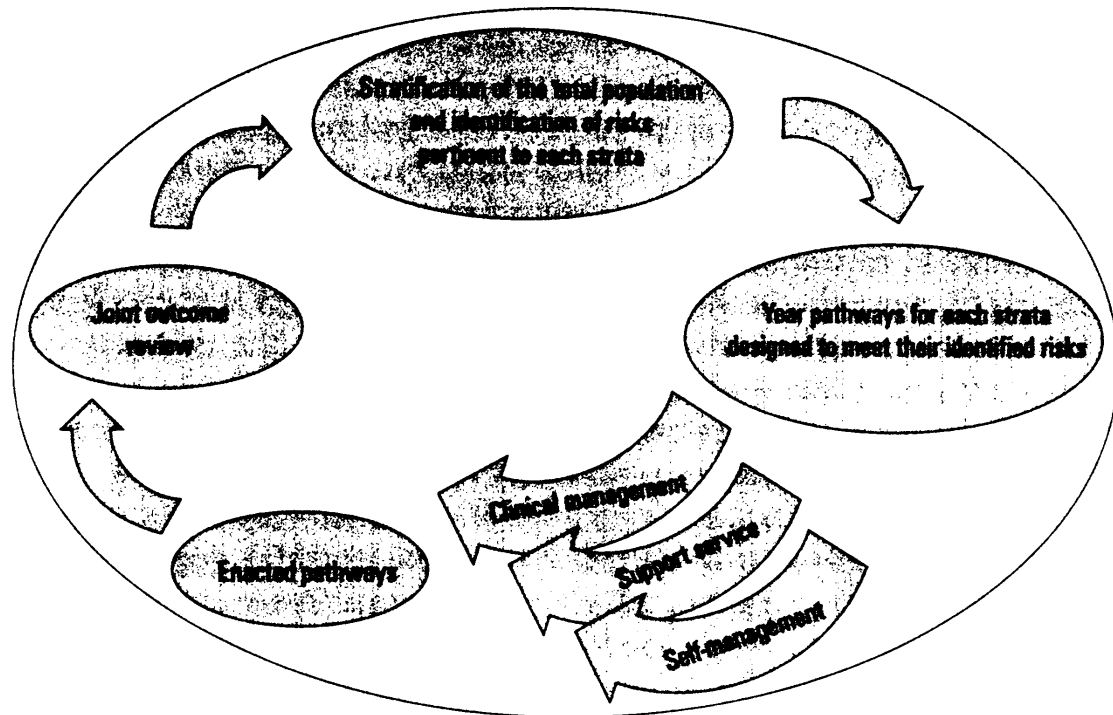


FIGURE 9.5 Population-based year pathway cycle

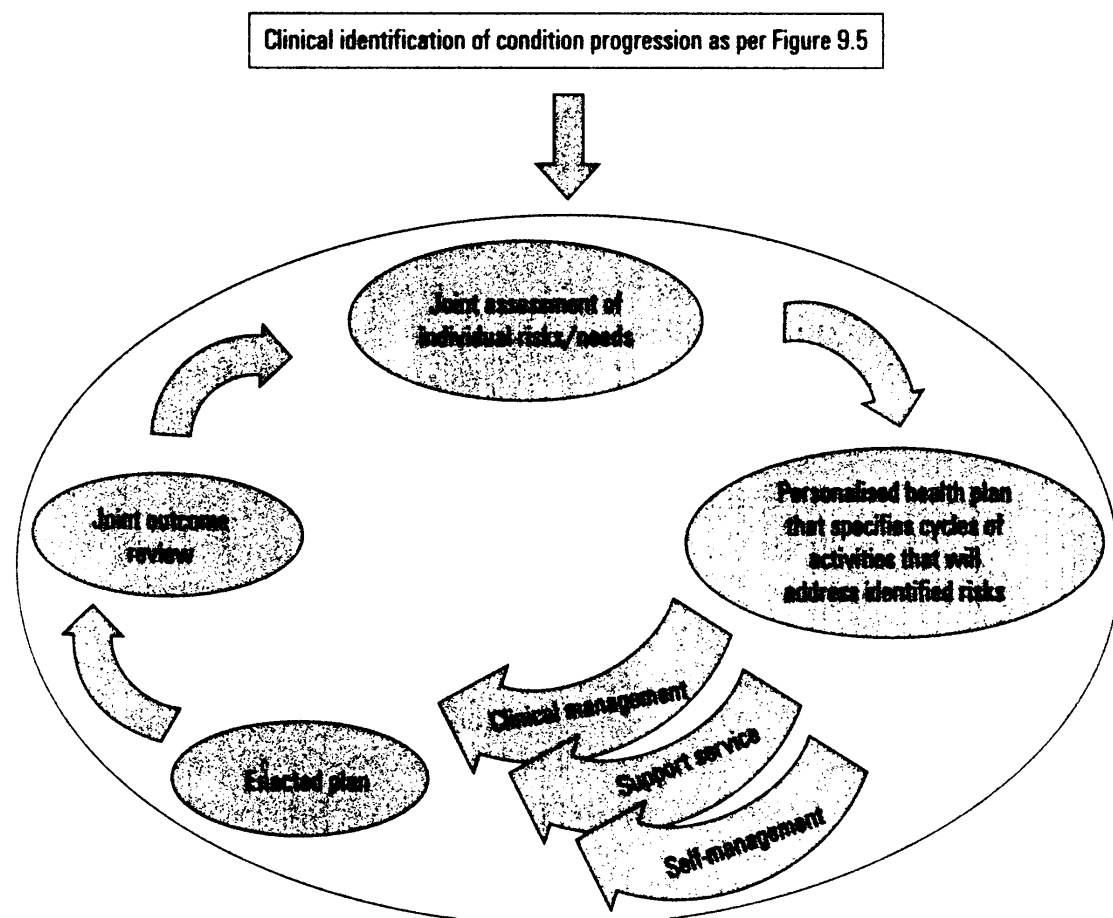


FIGURE 9.6 Personalised year plan cycle

levels. The focus on risk rather than need is intentional. It signals that the issues involved in this stage are more to do with process rather than technical criteria. Moreover, the principles of co-production and the injunction that service planners and providers look 'with' rather than 'at' people with long-term conditions, the assessment processes at both population and individual levels are structured to ensure that their view of what is at risk is heard and heeded. The focus is not merely on clinical factors but also on what is at risk from the perspective of the individual and/or their carers. Thus, the risk assessment includes not merely factors that determine the clinical profile of a population or individual but also other factors such as social or economic circumstances, environmental factors, living circumstances and health related factors whose presence or absence (either singularly or in combination) 'prevent people from achieving the optimum of physical, mental and social well-being'.<sup>22</sup>

The foregoing is not to suggest that the focus of risk assessment will be the same at both population and individual levels, or that it is straightforward. The aggregated nature of population oriented assessments means that they will depend more on normative and comparative criteria that have been derived by experts whether clinical, epidemiological or sociological. Consistent with the design features of our model, individual focused risk assessment will place a weight on personal experiences and feelings. This characteristic, in turn, is likely to introduce complications that are 'masked' at population level.

Service planning will occur at two levels. *Population-based service planning* will occur as primary care trusts or local health boards, on the basis of the risk assessment processes outlined above, act to develop year-based pathways that for each level of service provision (self-management of health, care management and case management) specify the cycles (daily, weekly, monthly, yearly) of sequences of activities that will be undertaken by people with a long-term condition, informal carers, service providers, and support services, whose occurrence or non-occurrence (according to the best available evidence, NICE advice and 'expert patient advisers') will significantly affect the quality, outcomes and cost of service provision. On the basis of these year plans the commissioner will act to ensure the availability of the support services that will be incorporated into individualised year plans. These services include condition specific education and support groups, expert patient programmes, routine reviews by nurse practitioners with expertise in chronic disease management, health enhancement programmes (e.g. exercise and smoking cessation), and pooled budgets between health and social services.

*Individualised year (case, care and/or health) plans* will be developed as an individual with a long-term condition as principal) negotiates an agreed year plan (case, care and/or health) with service providers (the agents). These plans (case, care or health) will take the form of a comprehensive written statement that specifies the agreed risks that a plan is meant to address and the outcomes that it is designed to produce; that is, the cycles of activities (daily, weekly, monthly) that will be undertaken by the individual, clinical staff and support

service staff at specified times within a cycle and whose occurrence or non-occurrence (in the light of the jointly conducted risk analysis) will significantly affect quality, outcomes and cost. Individual plans thus comprise elements of self-management, care support and clinical management and they are the property of the person with a long-term condition and a means for recording the performance of each party to the plan.

Finally, the third systemic dimension is the improvement oriented evaluation, performance management and clinical governance. Consistent with the centrality we have given to risks as perceived by both the person with the long-term condition and service providers, evaluation processes will focus on the extent to which co-production in the course of a specified time period by way of self-management, support services and clinical services as described in the pathways and individual plans meet identified risks. The methodology (see Figure 9.7) thereby provides means for translating expressed wants and priorities of the person with a long-term condition into a time-based pathway which, once described, can be monitored and then managed. It also enables the identification of the extent to which there has been health gain from Line A to Line B in Figure 9.1.

That said we are left with questions about 'what we do about a hospital admission'. First, we need to be clear that a hospital admission is not part of either a care plan or a Year of Care pathway. One of the main reasons for having a year plan is to engender and support a co-production process

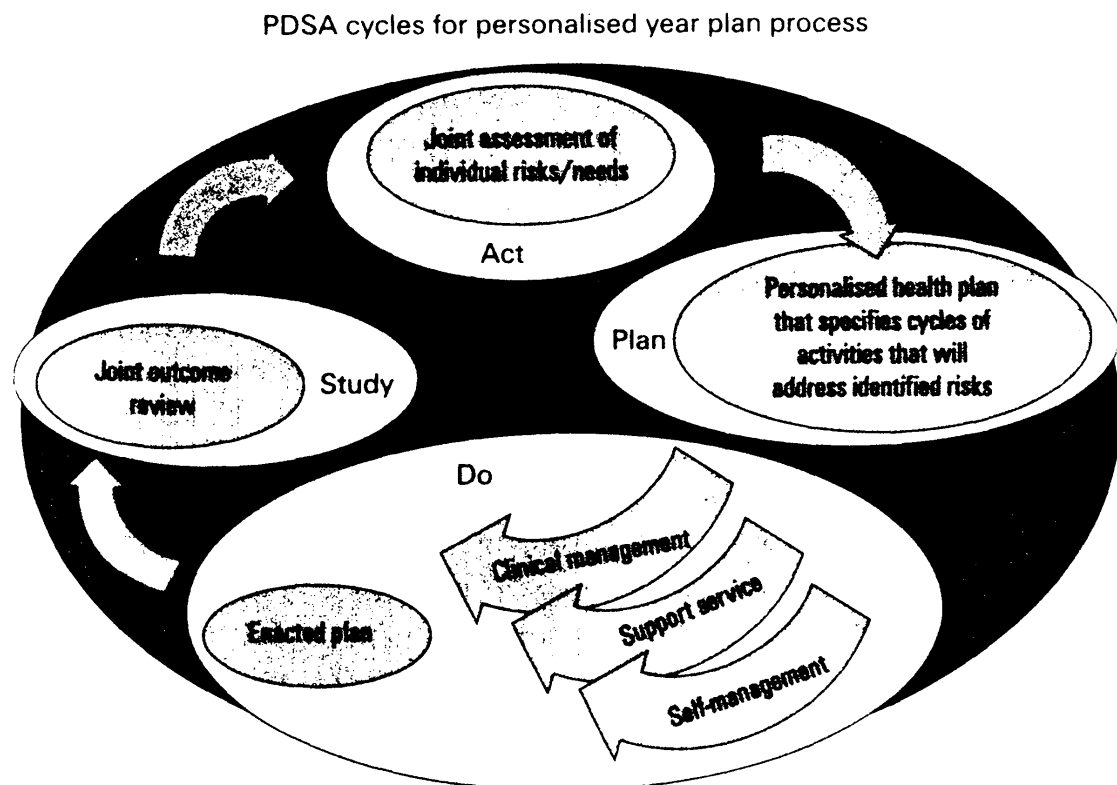


FIGURE 9.7 Plan-do-study-act (PDSA) cycles for personalised year plan process



that in the interest of quality of life, clinical efficacy and resource efficiency keeps people out of hospital. That being the case, the occurrence of an acute admission has the status of a significant variation to an individual's plan and, as with other outcome variations, the reasons for this should be investigated in the 'study' of the plan or pathway PDSA cycle, particularly where there is evidence a significant number of admissions for health/care/case plans for a nominated condition.

## CONCLUSION

Our analysis of current models of service provision to people with long-term conditions demonstrates how provision is undermined by clinically dominated constructions of such persons as dependent patients whose individuality is buried by the clinical deficits and needs that are ascribed to them by clinicians. In contrast, we argue that the inherent link between the body and the self calls for a model, within which people with long-term conditions are recognised as sentient beings who retain ultimate responsibility for their health as well as the right to exercise their voice and volition in constructing and determining their lives. These rights and responsibilities, in turn, are inscribed in their relationship (as principal) with carers (as agents) with whom they co-produce their health. Accordingly, the process through which services are designed and delivered should be structured along lines that enshrine the rights and responsibilities of people with long-term conditions to be informed, to be consulted and involved in decision making and to enter agreements with agents (clinicians and other carers) that specify what they (as principal) can expect from others and what others can expect from them.

These characteristics (illustrated in Table 9.2 and elaborated further in Degeling, *et al.*<sup>23</sup>) provide the basis for systematising service provision in respect of:

- the existence of *explicit methodologies* for (1) stratifying the populations that fall within the ambit of specified long-term conditions and (2) identifying both their clinical risks as well as their risks, wants and priorities as they see these to be
- a *person authorised and accountable* for integrating services at a personal level
- integrating *methodology* specifying how identified risks and priorities will be linked with a specified menu of services from within the health service but also from other sources such as social services, the voluntary sector, community sources and informal carers
- a care plan as an *integrating artefact* that (1) specifies who will do what, why, when and where, and (2) records the responsibilities and rights of all parties
- an improvement oriented *performance management and review process* that (1) routinely and systematically examines service performance in

respect of its appropriateness for meeting the specific needs and wants of each population strata and (2) sets the agenda for ongoing service improvement as defined above.

In summary, the Year of Care model encourages specificity and clarity along four dimensions. First, it distinguishes between three levels of the population. Second, by recognising the coterminosity of the self and the body, the model provides means for integrating both the personal health responsibilities of individuals and their rights to have their voices heard and heeded in the co-production processes. Third, it provides a basis for risk assessment and service planning to take place at a population level and an individual level. Finally, it provides a framework for making fully explicit (in contrast with existing models; *see* Table 9.1) both what comprises each of the elements of care (self-management, support and clinical), and how they will be related to each other on a person by person basis in ways that enable service provision to be prospectively and proactively designed, explicitly defined, planned and coordinated.

**TABLE 9.2** Summary of Year of Care programme stratified service provision

	<b>Level 3 Case management</b>	<b>Level 2 Care management</b>	<b>Level 1 Self-management</b>
<b>Population criteria</b>	<b>Population identified using both clinical indicators and personal indicators such as:</b> <ul style="list-style-type: none"> <li>• high score on Hospital Anxiety and Depression scale</li> <li>• nature of family dynamics/dependants</li> <li>• health literacy</li> <li>• self-efficacy.</li> </ul>	<b>Population comprises persons with a single condition or range of clinical problems, and personal indicators such as those shown in level 3, who would benefit from care management.</b>	<b>Population defined as those at high risk of developing a long-term condition, due to a combination of clinical risk factors (high BMI, family history) and personal psycho-social risk behaviours (smoking, alcohol etc).</b>
<b>Identified primary integrator</b>	<b>Individual as principal and community matron as agent:</b> <ul style="list-style-type: none"> <li>• with authority to order clinical investigations, make referrals and arrange admissions to hospital</li> <li>• who is the fixed point of contact for the patient</li> <li>• coordinates contributions of other professionals and agencies.</li> </ul>	<b>Individual as principal and primary care clinician as agent who:</b> <ul style="list-style-type: none"> <li>• acts as a point of contact between the individual and team</li> <li>• support individual to navigate services.</li> </ul>	<b>Individual as principal:</b> with support by primary care clinicians responsible for linking individual with secondary prevention support.

*cont.*

	<b>Level 3 Case management</b>	<b>Level 2 Care management</b>	<b>Level 1 Self-management</b>
<b>Service aim</b>	To improve quality of life and reduce repeat admissions.	To improve quality of life, extend active life, slow down disease progression, reduce disability, ensure better management of sudden deteriorations, reduce need for hospital admission and improve quality of life.	To improve quality of life and reduce risks of developing a long-term condition, and if diagnosed to reduce its severity.
<b>Method</b>	<b><i>Case management</i></b> <ul style="list-style-type: none"> <li>• Joint negotiation of individualised case plans that are based on a trade-off of the different constructions of the risks that are in play on an individual by individual basis.</li> <li>• Emergent variations, managed by the community matron as case manager.</li> </ul>	<b><i>Care management</i></b> <ul style="list-style-type: none"> <li>• Stratified, condition specific registers.</li> <li>• Time specified recall and review process.</li> <li>• Condition specific networks that span primary and acute settings.</li> <li>• Negotiation of individualised care plans based on a trade-off of the constructions of risk that are in play as these are perceived by the individual and clinicians.</li> </ul>	<b><i>Health management</i></b> <ul style="list-style-type: none"> <li>• Stratified registers identifying those at high risk of developing a long-term condition.</li> <li>• Time specified recall and review process.</li> <li>• Joint negotiation of an individualised health plan that registers trade-offs between risks as these are seen by individual and clinicians.</li> <li>• Provision of secondary prevention support.</li> </ul>
<b>Artefact</b>	<b><i>An individual case plan that is held and owned by individual which specifies</i></b> <ul style="list-style-type: none"> <li>• the details of the care to be provided</li> <li>• regular reviews to re-assess risk</li> <li>• the self-care to be undertaken by the patient and informal carers</li> <li>• what each professional and agency will do to meet need, manage risk and/or support self-management.</li> </ul>	<b><i>An individual care plan that is held and owned by individual which specifies</i></b> <ul style="list-style-type: none"> <li>• the details of the clinical care to be provided</li> <li>• regular reviews to reassess risk</li> <li>• the self-care to be undertaken by the patient and informal carers</li> <li>• what each professional and agency will do to meet need, manage risk and/or support self management.</li> </ul>	<b><i>An individual health plan, held and owned by the person and specifies:</i></b> <ul style="list-style-type: none"> <li>• the health objectives that the individual will pursue</li> <li>• the activities that will be undertaken in this regard</li> <li>• the support services that can be drawn on</li> <li>• regular reviews to reassess risk.</li> </ul>
<b>Performance management and review</b>	<b><i>Time specified application of PDSA methodology</i></b>	<b><i>Time specified application of PDSA methodology</i></b>	<b><i>Time specified application of PDSA methodology</i></b>

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